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Testimony of Shelagh McClure, Chair
Connecticut Council on Developmental Disabilities
Before the Human Services Committee
On Senate Bill 17
February 18, 2016
Submitted to: hstestimony@cga.ct.gov

Senator Moore, Representative Abercrombie, members of the committee. Thank you for the opportunity to present testimony on Senate Bill 17, An Act Implementing the Governor's Budget Recommendations for Human Services.

I am Chair of the Connecticut Council on Developmental Disabilities, a public agency whose mission is to promote independence and full inclusion of individuals with developmental disabilities in their communities, and to foster capacity building and system change. With a number of partners, including the Office of Protection and Advocacy, The Arc Connecticut, the Center for Excellence in Developmental Disabilities at UConn and the Cross Disabilities Lifespan Alliance, we have called for the closure of all state-operated institutions for individuals with intellectual disabilities by the year 2020. I am also the parent of a 25-year old son with an intellectual disability who lives at home with my husband and me.

Since 2012, the DDS budget has been cut by over \$60 million dollars. Two thousand people are on the Waiting List for DDS residential services, and, beginning in FY 2016, a new waiting list for Employment and Day Services was created due to funding cuts. There are nearly 800 people on the Autism Services waiting list. The DDS system is in crisis, and since we face a worsening fiscal landscape, this system, which in bad times has failed so many individuals it was intended to serve, can hardly be expected to perform better in worse times. So change is needed.

This bill proposes two significant changes to the DDS system: first, to create a new Intellectual Disabilities Partnership, modeled after the Behavioral Health Partnership; and second, to transfer the Autism Division within DDS to DSS. At this time, not enough is known about either of these proposals, and that leads to my first comment.

There are few who do not agree that major changes are needed to improve the delivery of services for people with I/DD in Connecticut, but I have not talked to anyone who knew in advance of these proposals. With so many stakeholders—individuals with intellectual and developmental disabilities and their families, and providers of services—it would have been far better to have provided information in advance, and sought input from those who will be affected by these changes, rather than rolling out major system change proposals without any prior notice, especially in a short session of the General Assembly. If these proposals are to move forward, a more open and collaborative approach is crucial. And much, much more information is needed. The lack of information limits our ability to comment on the bill, but we offer the following for your consideration.

Since these proposals came out of the blue, in your shoes, our initial question would be: **how will these proposals improve the delivery of services to individuals with intellectual and developmental disabilities**—that is the budget priority identified by the Governor. Because here is the fear of parents and family members of individuals currently unserved or underserved in the DDS system—that these will be just other ways to cut the budget on the backs of people with I/DD, dressed up as system reform.

Specifically, how will creation of an Intellectual Disabilities Partnership

- alleviate the 2,000 person Waiting List for residential services
- address the new waiting list for day and employment services
- solve the inadequate rate structure for private providers
- reduce the excesses and inefficiencies in the publicly operated facilities and speed the closure of public institutions so that savings can be redirected to expand services

How will transfer of the Autism Division to DSS

- Alleviate the nearly 800 person waiting list for services

These questions do not mean that the Council is not supportive of system reform. But unless reform is true reform of the entire system, that also addresses the failure to serve so many individuals needing services, it is hard to see how it will be affordable or fair.

Some specific comments on the Intellectual Disabilities Partnership proposal:

Today, too many dollars are expended on the publicly operated facilities serving too few individuals. Southbury Training School costs over \$365,000 per person per year and the Regional Centers cost over \$440,000 per person per year, well over double the cost of community-based placements. Nearly \$90 million could be saved (enough to serve 1,000 people on the DDS residential Waiting List) if all 468 residents of the state-operated institutions were moved to high quality private settings in the community.

In Public Act 15-1, sec. 23 (DSS), the General Assembly directed OPM and DDS to produce a report by December 2016 on a plan to implement the closure of DDS public facilities, expressing the legislature's clear intent to close DDS institutions. So the language in Section 1, para. (7) of SB 17, which states the partnership will seek to

increase access to quality services for persons with I/DD by “reducing unnecessary use of institutional services” (emphasis added) is problematic. Placing this function within the proposed partnership introduces uncertainty regarding the already stated intent to close institutions (not reduce usage of the facilities).

At a minimum, this language in para. (7) could delay action on institutional closure, since this partnership is years from full operation (the Behavioral Health Partnership took 4 years to become fully operational), to the detriment of both the institutions’ residents, who have a right to live in the community, and unserved and underserved individuals who won’t receive the benefit of the savings from institutional closing. The Council recommends that the language “reducing unnecessary use of institutions” should be eliminated from the bill. If language regarding institutions is to be included, it should state instead “accelerating the closure of state institutions” consistent with the directive of P.A. 15-1 section 23 (DSS).

It is also not clear what is meant by the language in the same para. (7) under section 1 “reducing unnecessary use of. . .residential services;” particularly in light of the language in para. (10) “identifying strategies to make resources available to address the waiting list for residential services in the Department of Developmental Services.”

Clarity on this point is critical. Providing community-based residential services is a core function of DDS, as identified by the department itself. How the partnership and DDS will interact in fulfilling that function is not clear. But provision of appropriate community-based residential services and supports for individuals with I/DD based on their needs, including expanding resources so that individuals on the waiting list receive services should not be placed in doubt by unclear language in this bill.

The Council encourages the committee to substitute the following language for the current language in section 1 (7): “providing a continuum of community-based residential services and supports for persons with intellectual disabilities based on their needs.”

Finally, a few general comments. With regard to the makeup of an oversight board for the partnership, it is crucial that families and self-advocates are represented. The oversight board should have authority to approve rates; the rates must be adequate to actually pay for the cost of the underlying service, so that Connecticut can have a healthy provider network. Since this bill proposes to move to a managed care approach, DDS must acquire in-house managed care expertise.

The role of the partnership in relation to DDS—or to be clear, what changes for individuals with I/DD and their families when the partnership is up and running—needs to be explained if support from the community served is to be achieved. We look forward in the coming weeks to hearing these details, which we hope you, the Human Services Committee, will demand before taking any action on this bill.

Thank you for the opportunity to present this testimony.